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ABSTRACT

This study examined provision of services to children with developmental disabilities and their families in the context of requirements of Part H of the Individuals with Disabilities Education Act, which requires family centered services for infants and toddlers. Focus group discussions were held with health professionals at two sites in each of five states. The discussion revealed three broad themes. These were: generic needs of families who have infants and toddlers with disabilities (e.g., needs for day care and respite care); extenuating needs (e.g., needs caused by poverty, lack of transportation, lack of education, isolation, or cultural diversity); and social policies (e.g., problems generated by restrictions on Medicaid services and Medicaid eligibility requirements). Emphasis is placed on the tremendous responsibility faced by families of children who are developmentally delayed as their needs far exceed the routine and customary. Includes eight references. (DB)

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SHORT REPORT

February, 1992

Carolina Policy Studies Program

PROVISION OF SERVICES TO INFANTS AND TODDLERS WITH DEVELOPMENTAL DELAY: THE HEALTH PERSPECTIVE ON FAMILY AND SOCIAL ISSUES

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Introduction

The following paper on family and social issues emerged from an exploratory study conducted by the Carolina Policy Studies Program (CPSP) on the implementation of Part H of IDEA (formerly P.L. 99-457). The focus of this study was on how health professionals provide services both to children who are developmentally disabled and to their families. We sought the perspective of health professionals because they often have the initial contact with families of infants and toddlers. Moreover, the interaction between families and professionals from the health community often is sustained over long periods of time.

The Carolina Policy Studies Program held a series of focus group discussions with health professionals at two sites in each of five states. The states (Colorado, Hawaii, Maryland, North Carolina, Ohio) were selected for their geographic and cultural diversity and leadership in meeting both the needs of children with disabilities and the needs of their families.

Health professionals were nominated in each of the states through recommendations of professionals and parents who were involved in programs for young children with disabilities. Those who were recommended were invited to participate in open-ended focus group sessions in which CPSP staff encouraged the discussion of all significant issues related to provision of services.

Out of these open-ended discussions emerged several themes that seemed to have direct bearing on policy implementation in the states. The topics on which the discussions focused transcended state and regional boundaries, and were national in scope. This report describes concerns expressed by these health care providers about ways in which family and social issues can have an impact on the provision of health care to young children and infants who are developmentally delayed.

Background

Family-centered care is a major goal of Part H of IDEA. The authors of this legislation recognized the critical importance of participation by families in all aspects of their child's care and development. Family-centered care acknowledges the strengths of the family unit and encourages parent and professional partnerships that can be directed toward the enhancement of the child's development.

Family-centered care can provide an environment that is nurturing and highly conducive to obtaining maximum growth and development for each member of the family unit. In order to strengthen the family unit, numerous commissions, research projects, and policy-analysts have called for social and economic support (A. Schorr, 1986; L. Schorr, 1988; Flynn & McCollum, 1989; Pearl, Brown, & Myers, 1990; W.T. Grant Foundation, 1988), so that families have

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adequate resources to provide optimal care for their children. This a most urgent need for parents of infants and toddlers who are developmentally delayed (Place, Anderson, Gallagher, & Eckland, 1991).

Families with infants and toddlers who are developmentally delayed or otherwise handicapped face many adjustments. First, they must learn to reconcile their expectations for a healthy child with the realities of a child who is ill, delayed, or disabled. They need to acquire knowledge about their child's condition, and about the medical and developmental treatment and prognosis of the disability or illness. In addition, these parents need to acquire specialized knowledge and skills in order to care for their child, and to monitor the care provided by others. They need to become knowledgeable about health-care financing, including health insurance regulations and restrictions. The availability of a variety of human service agencies, and means of gaining access to needed and desired services may become part of their knowledge base. All of this and more must be combined with routine responsibilities and obligations.

As this present report on the relationship between family and social issues and the health of children who are delayed suggests, adequate support for families remains an unachieved goal. Greater community based support is needed for these families at all socioeconomic and educational levels. The needs remain most critical at the lowest levels of education and economic attainment. Healthy People 2000 (U.S. Department of Health and Human Services, 1990) reported, for instance, that low levels of education and socioeconomic status are associated not only with higher levels of developmental delay in infants and children, but also with a lack of attention to health and developmental needs and, concomitantly, with a lack of health insurance or any other means of securing services. This report concluded by noting that "a wide range of social and economic interventions" (U.S. Department of Health and Human Services, 1990, p. 15) was needed to improve the education, health, social, and economic conditions of American children; the report recommended support programs for parents and families.

Findings

Findings resulting from this study underscored three broad themes related to family circumstances. First, there were generic needs of families who have infants and toddlers with handicapping conditions. Most families, for example, could benefit from substantial emotional support and a network of assistance that includes the community, families, and friends. In addition, some families have numerous and overwhelming extenuating concerns, of which a child who is delayed or disabled is but one. And, finally, many families face constraints from social policies that can affect the care received by a child.

Generic Needs. All families with children have at least occasional need for child care that is provided by someone other than the parents or family members. There are appointments and obligations where the presence of a child or infant is neither appropriate nor desired. Both parents may work or the family might be headed by a single parent who works. Caregivers are not easy to find, and, often, the greater the need for specialized care, the more difficult it is to find qualified and appropriate care.

The pressure of constant care of an infant or toddler who is delayed ill, or disabled places numerous stresses on parents. Many of the health-care professionals expressed concern over the responsibilities faced by parents of children with developmental disabilities. They spoke of depression among parents:

> ... the depression and anxiety and the stress on the families is unbearable as time goes on ... (Pediatrician in private practice)

of a breakdown in family life:

> ... the family no longer is a family, they become a mini hospital centering around the kid's life ... (Pediatrician in private practice)

and, of families dissolving:

> All too frequently ... the trauma of a multi-

> handicapped child breaks up the family. (Pediatrician in private practice)

The empirical literature on the coping skills of families with handicapped children indicates that their parenting skills and behaviors are not different from families with children who are without handicapping conditions (Bristol, Gallagher, & Schopler, 1988). The families who were studied and reported on by Bristol and her colleagues, however, typically were involved in programs that provided extensive and comprehensive services to families and children. The children, moreover, often were older pre-school aged, or even school-aged. In the birth-to-three year old population who are developmentally delayed, the family may be in the initial stages of learning that the child has a handicapping condition and the child may: (a) present significant medical, or life-threatening conditions; (b) be severely disabled or delayed; and, (c) not be in an on-going developmentally-oriented treatment program. Each of these factors can have significant implications for the parents and family.

A system of day- and respite-care provided through the services of highly-skilled staff was discussed in our focus group sessions and was viewed as providing the relief that is desperately needed by many parents, even those who are coping extraordinarily well:

> ... [the] child with complex health care needs, as well as children who are at risk ... can be in a day care ... there's a real void in that area and it's keeping families isolated. (Developmental pediatrician in a university hospital)

> Families become house bound for two years after a high risk preemie comes home ... provision of respite care is one of the issues. (Nurse in a community hospital)

Day-care can provide needed support for families; it also can provide the locus for coordination of many different types of services. While a few participants in our group discussions expressed a reservation that day-care could erode family influence and participation, most seemed to feel that day care of high quality was a serious need.

Extenuating needs. It was felt that the above issues pertained to virtually all families with a child who is developmentally delayed or disabled. In addition, when families were faced with conditions of poverty, lack of education, isolation, or cultural diversity, the optimal care of the child was at further risk. Our discussions suggested concern of considerable magnitude on the part of health care providers for the children and families who were experiencing these difficulties.

For instance, for the poor, the working poor, and for teen age parents transportation can present a huge barrier to access of health care:

> ... if people don't have a car ... What if you're 15 and you don't have a driver's license ... how do you get your child in. (Neonatologist in a community hospital)

> [or], a parent that came with four kids on the bus, making their two connections to get here. (Pediatrician in private practice)

The lack of transportation creates one form of isolation. Social diversity and economic difficulties can create another form:

> ... we are dedicated towards getting people who might not otherwise be health utilizers ... finding families who in urban situations tend to be a bit more mobile than in rural ... moving without a forwarding address, telephone number. (Developmental pediatrician in an inner city teaching and research hospital)

In addition, an infant or toddler with developmental delay may be just one of

many concerns within a family. For example, there may be other needs, or another family member may be sick or disabled:

> ... the father was eventually [laid] off on disability because of back problem. They also had two other children and those children had problems. ... and if they don't have any food in the house, they don't care that they have a neurology appointment on Friday. (Nurse in a public health department)

Our discussions suggested that families who were stressed by many layers of difficulties may need assistance with these other issues in order to care for a child who was disabled or delayed. Family-centered care relies heavily on individual responsibility. Individual parents must recognize that their child has a need (e.g., health, developmental stimulation), understand how to fulfill the need, and obtain the resources necessary to do so. These health-care professionals were expressing their concerns about the ancillary support needed by parents in order to fill this role and of the overall absence of any system through which to provide support for extenuating needs of families.

Most families with children who are disabled or delayed have needs that are continuous over the long-term and require coordination among multiple disciplines and agencies. At the present time, care and services that are provided in a continuous and coordinated manner are not universally available, but rather a "mishmash of rather poorly fitted-together services dictated by federal, state, and local politics and money" (Pediatrician in private practice).

Social policies. Medicaid, which was established under Title XIX of the Social Security Act Amendments of 1965, was conceived as a means by which the poor of this nation could gain access to health care. Medicaid has had an impact on numerous aspects of health care, such as lower infant mortality rates and increased childhood immunization rates. Medicaid has rigid requirements for the types of treatment allowable under its reimbursement guidelines, however. It, as well as coverage from private insurance providers, has been biased in favor of medical care that is procedural and away from health care that has a cognitive, social or emotional basis, such as developmental stimulation, counseling, or assistance with coordination of multidisciplinary care. More recently, Medicaid policies have been adopted that ameliorated the exclusion of professional practices that incorporated cognitive or social approaches.

The physicians and nurses with whom we spoke, however, described a continuing need for providing support to parents in the form of listening to the concerns and needs of parents, for training and education about the particular needs of the child, and for assisting the parents with an array of activities that ranged from the coordination of care for their child who was delayed or disabled to the resolution of family financial difficulties. Current restrictions imposed by the state's implementation of Medicaid, however, can limit or alter the care provided to the child:

> there's general community lack of acceptance of Medicaid ... and so its very limiting in who you can send kids to. (Pediatrician in a private practice)

or, even interfere with the bonding process between the family and their infant or young child:

> ... the deal we struck with the mother who couldn't stay in the hospital any longer because Medicaid wouldn't allow her. (Pediatrician in a community hospital)

In addition, the financial means tests for determining Medicaid eligibility were reported to be interpreted in an idiosyncratic manner and to require an incredible amount of documentation from applicants:

> ... and the counties vary because over there ... there are two people who take the medicaid application and you're told which one to go

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> to 'cause if you go to the guy called [Joe] ... he's always going to turn you down. (Developmental pediatrician in private practice)
>
> ...[a] major barrier is the complexity of filling out forms and the amount of documentation that I will have trouble finding at my house ... to apply for Medicaid. (Pediatrician in a community hospital)

While Part H of IDEA encourages care that is family-focused and community-based, the stories related by these health-care professionals indicated that other governmental policies or agencies may actively interfere with meeting this challenge. Moreover, these experiences suggest that significant modification of health, social, and economic structures may be required in order to provide the care that is needed, as well as to meet the challenges posed by Part H.

Summary and Discussion

The development of infants and toddlers occurs within the context of their environment. Central to the environment of a young child is its family, and the physical, emotional, social, and economic circumstances of the family. The importance of the family to the optimal development of infants and children was a theme that was central to the discussions we held with physicians and nurses.

A prevailing view expressed in our focus group discussions, and in the public and scholarly literature, is that most families can function independently without intervention from outside sources. Most families find health-care when needed, as well as day care, supplemental services, or schooling; payment is made for services received. As a nation, we have traditions that reinforce independence and responsibility by the individual and the individual family unit. Family-focused care continues and reinforces the tradition of independence and individual responsibility. But, the responsibity that must be assumed by the families of children who are developmentally delayed is tremendous and the stress can be overwhelming, as the needs of many of these children far exceed the routine and the customary.

Community-based care challenges professionals and parents to search for new ways to provide services to our nation's most vulnerable citizens. That search may lead to a recognition that all families and children are in need of services, and that the degree of need can be expressed along a continuum. The recognition of universal need may, in turn, facilitate **Inter**dependence among various sectors of the community--parents and children, as well human service providers, and representatives from business and government organizations--and a realization that interdependence can strengthen the fabric of our society.

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